



Transplant/ 'A walking sick person'

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Twice as many white people are registered organ donors than are waiting for a transplant, but that's not the case with minorities.

Advocates say the lack of minority organ donors is a continuing nationwide challenge.

Since 1988, people from minority groups have outnumbered minorities willing to donate organs, according to the Organ Procurement and Transplantation Network.

The United Network for Organ Sharing says minorities develop some diseases more frequently than whites and rejection after a transplant drops dramatically when organs go to genetically similar recipients. A shortage of organs donated by minorities can contribute to their death and longer transplant waiting periods.

But in Nevada, donations from whites have been declining since 1999, when 82 percent of donors were white. This year, 57 percent have been white, according to OPTN.

Meanwhile, the donation rate for Hispanics doubled to 24 percent from 12 percent in 2002. Blacks have been inching up since a low of 2 percent in 1999 to 9 percent this year.

In Clark County, where blacks are 9 percent of the population, a yearlong campaign recently was launched to encourage at least 500 blacks to register to become organ donors, said Robert Mirisch, executive director of the nonprofit Las Vegas-based Second Chance Foundation. His staffers choose a minority community to target each year, typically through religious leaders. In 2003, the Jewish community was targeted and last year Hispanics.

No campaigns have been discussed for Washoe County, where blacks make up 2 percent of the population.

"This issue has an 'ick' factor," Mirisch said of organ donation. "No one likes to think about end of life issues. They don't like to buy cemetery plots and think they're immortal until something happens. That's our whole problem in the field of organ donation."

William J. Minniefield, founder of the Minority Organ Donation Education Program in Buffalo, N.Y., said mistrust and religion affect black organ donors.

"The number one reason minorities, especially blacks, don't participate in organ donation is a mistrust in the medical system," he said. "Another barrier is religious beliefs. Many feel they need their eyes and organs to see on judgment day and they think to get into heaven, their bodies need to be intact."

He said the medical mistrust by blacks stems from the Tuskegee Syphilis Study, carried out in Macon County, Ala., from 1932 to 1972. In trying to learn more about syphilis, medical officials withheld adequate treatment from a group of poor black men who had the disease, causing needless pain and suffering.

"You'll still find that blacks think they are being mistreated by the medical community," Minniefield said.

Donation advocates say they are left to rely on educational campaigns targeted to individual minority populations to try to increase the number of those donors. In the late 1990s, basketball superstar Michael Jordan was the spokesman for the Coalition on Donation and in 2003 former basketball star and sports commentator Sean Elliot became the spokesman for the American Society of Minority Health Transplant Professionals. Advocates said those campaigns did little for the cause.

Minniefield said minorities favor organ donation when they are personally affected. He said his brother died waiting for a kidney and another brother suffered rejection after a kidney transplant and is seeking another kidney. Minniefield's niece died of cancer when she was 3 and her parents donated her corneas.

"We really need to instill in minorities that there is a need for organ donation," HE said.

Mirisch said virtually all religions have come to the conclusion that organ donation is a "great gift."

"It's a humane thing to do that is permissible and encouraged," he said. "But a lot hold on to old beliefs."

He said it's hard to tell if recent Las Vegas campaigns to increase donors work.

"I'd love to wave a wand and everyone would understand being an organ donor is the thing to do ...but you have the reality of culture and history and have to be as creative and sensitive to all the communities as possible to get the word out," Mirisch said. "It takes time."

He said the greatest misconception is that people, especially minorities, believe doctors won't try to save them if they are organ donors.

"That is factually not what happens," HE Said. "They don't even know you're an organ donor when you're being treated. It only comes up after you've been declared brain dead."

Mirisch and Minniefield agree there's no quick remedy.

"This is something that's going to take a while," Minniefield said. "We really need to focus on keeping people educated and getting rid of myths."